

It May Be Nonaversive, But Is It a Positive Approach?

Relevant Questions to Ask Throughout the Process of Behavioral Assessment and Intervention

Nancy R. Weiss

University of Delaware, Newark

Tim Knoster

Bloomsburg University, Pennsylvania

The technology of behavior modification is ethically neutral. It can be used by villain or saint. There is nothing in a methodology which determines the values governing its use.

Skinner, 1971, p. 150

It is important for people involved in the art and science of behavior change to reflect on the ethical issues inherent in this work. Simply because interventions are not inhumane or disrespectful does not, by default, make them person-centered or examples of positive behavior support. It is recommended that a series of questions be thoughtfully addressed when a functional behavior assessment is conducted and subsequent interventions and supports are designed. Specifically, the following questions should be considered: (a) Does the person have opportunities to express opinions and to control his or her life through meaningful choices? (b) What needs does the person address through his or her problem behavior? (c) How will our actions positively influence the person's quality of life? (d) How have the people who know and care about the person participated in the process? (e) How will the approach that is used affect the people implementing the procedures and others? (f) Would you use the interventions selected with a family member or friend? and (g) How will the behavioral interventions minimize the likelihood of crisis? Asking these questions can help to assure that behavioral interventions enhance the quality of people's lives and can help to reduce the emergence of crisis situations.

It is essential for those of us involved in various forms of behavior change endeavors to find time to reflect on and consider the ethical issues inherent in our activities.

It is tempting to believe that if we are not doing work that is disrespectful or inhumane we are acting in a person-centered manner. It is important to note that there can be a vast and dangerous gray space between those practices we know to be unethical and those that would be truly life-affirming.

In the spirit in which the concepts of positive approaches and positive behavior support are intended, it is important to recognize that every approach that does not rely on aversive or restrictive procedures is not by default a positive approach. Positive approaches are those that enhance a person's life and are characterized by collaboration versus control. Positive approaches are much more focused on *illumination* (understanding the meanings and purposes of the behavior from the individual's point of view) than on *elimination* (simply extinguishing a problem behavior). According to Carr et al. (2002), positive behavior support (PBS) is an applied science that uses educational and systems change methods (environmental redesign) to enhance quality of life and minimize problem behavior. Three major sources have served as catalysts to the evolution and maturation of PBS: the empirical basis of applied behavior analysis, the normalization/inclusion movement, and person-centered values (including self-determination). Carr et al. (2002) additionally noted that although elements of PBS can be found in other approaches, its uniqueness lies in the fact that it integrates critical person-centered features into a cohesive approach.

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There is no question that some people (with and without disabilities) engage in behaviors that are dangerous or seriously disruptive. Because all people are to be valued and respected equally does not mean that all behaviors are equally acceptable within society. Some people exhibit behaviors that are dangerous or that interfere with the quality of their own lives and/or the lives of the people with whom they interact. Professionals who work with people with behavioral challenges, family members, and other support providers have a responsibility to offer intervention and supports to people to help them change problem behavior. Our shared responsibility, however, is to do this in ways that value, enhance, and include people rather than through the use of methods that are coercive and controlling and on occasion can come dangerously close to manipulation or abuse. Another way to think about this (to paraphrase Carr et al., 2002) is that while behavioral science can tell us how to change behavior, our values help us consider (a) to which behaviors it is ethical to apply these methods and (b) what the parameters (acceptable norms) are within which to apply this science.

Positive behavior support uses the process known as functional behavior assessment (FBA) as a foundation. The FBA process is a problem-solving framework that leads to the design of interventions and supports that can lead to socially valid outcomes (Bambara & Knoster, 1995, 1998; Knoster, 2000, 2003; Knoster & McCurdy, 2002; Tilly, Knoster, & Ikeda, 2000). In particular, information is gathered about specific behavioral concerns and broad issues that reflect larger quality-of-life factors. As such, there are many important questions to be considered when conducting a functional behavior assessment and subsequently designing and implementing a person-centered behavior support plan. While not an exhaustive list, the following questions should prove helpful in better ensuring a positive approach and reducing the emergence of crisis situations.

Does the person have opportunities to express opinions and to control his or her life through meaningful choices?

Many ethical issues in the design and implementation of behavior change programs relate to issues of self-determination and locus of control. There is an inherent and inevitable imbalance of power whenever one person who has greater authority is trying to alter the behavior of another. This is often the case for people with disabilities who are placed in situations that exert unreasonable amounts of external control and deny opportunities to make basic life choices. Furthermore, history suggests that when a person with a disability exhibits difficult behavior there is a good likelihood that additional external

control will be added in the name of intervention. While it is not always wholly inappropriate to add some controls, the addition of greater degrees of restriction should be consciously and carefully weighed in every situation in which it is considered.

There is an unfortunate cycle that operates in some special education programs as well as in some programs for adults that seek to comprehensively manage people's lives. The typical cycle starts when the person of concern attempts to assert a degree of influence over aspects of his or her life that he or she perceives as being in the control of others. This is a natural response of people who feel powerless. Having few other options, many people who find themselves in what they view as restrictive and ill-suited environments protest this external locus of control by behaving in ways that are challenging. In response, caregivers are likely to increase restrictions in an effort to suppress the "rebellious" behavior. Staff will often describe this perceived need to add controls by saying, "A more structured environment is needed," rather than, "We need to apply more controls or restrictions." In response to increased external control, the person may escalate his or her problem behavior in an attempt to assert his or her will further. Since the person's behavior may appear to have gotten worse, caregivers are likely to determine that they were correct in assuming that more "structure" was needed and in turn look to add more controlling measures—which continues the cycle. Rarely does a cycle of this kind result in positive change for either the person being supported or those attempting to provide support. As the cycle of control builds, it can result in less inclusive and less satisfying lives for the people we support. In response to such adverse situations, family members may appropriately protest such control-oriented interventions. For example, one mother objected to her son's behaviors' being referred to as "power struggles" by staff. She noted, "A more accurate term might be that my son is provoked into a 'struggle for existence' pitted against totalitarian control—a struggle for autonomy, growth, and personal identity" (A. Salinski, personal communication, October 8, 2002). It is not only ethically suspect but programmatically illogical to respond to the increasing attempts of a person seeking to assert control over his or her life by wielding greater and greater amounts of power over him or her.

Although few programs identify themselves as supporting the use of aversive procedures, many are willing to limit choice-making and control to a degree that can become coercive. A visitor to a group home noted a posted schedule that indicated when it was allowable for residents to have a snack, when they needed to be in their rooms in the evening, and what time they needed to have

their lights out. Even though such regimentation does not fit classic definitions of aversive procedures, restrictions such as these are outside those that would be tolerated by most adults and therefore often result in rebellion. The cycle just described illustrates the manner in which small acts of protest can escalate to full-blown crises, and the risk exists for staff to react to crises with aggressive, reactive procedures.

What needs does the person address through his or her problem behavior?

Numerous authors have noted that a person with seriously difficult behavior is unlikely to be acting out of a desire to be troublesome but rather acts as he or she does because some need (i.e., function) is unmet and/or the person feels as if others are not listening to him or her (Carr et al., 2002; Knoster & Lapos, 1993; Lovett, 1996; Pitonyak, 1994). Modifications to programs, environments, and demands are more relevant to positive changes in behavior than programs directed at changing characteristics of people. Our efforts need to focus on providing opportunities for full lives of meaning and impact as opposed to attempts simply to modify programs and services that by nature are controlling and restrictive. While it is true that “need is the mother of invention,” it may also be argued that invention is the mother of need. For example, most of us did quite well 15 years ago without cellular phones or e-mail. However, now that these technologies exist, it is hard to imagine life without them. We understandably become habituated to using what we have and what we know. In much the same way, professionals seeking to change people’s behaviors are often overly reliant on the technology of contingency manipulation for the exclusive purpose of behavioral control. Simplistically strict operant approaches can be seductive on the surface. They seem so clean, logical, empirical, and—in this age of emphasis on good record keeping—so neat to count, measure, and document. Sadly, and not surprisingly, programs based exclusively on short-term consequence manipulations do not typically lead to durable, socially valid outcomes or to richer, more inclusive lives for the people we support (Carr et al., 2002; Ervin et al., 2000; Lucyshyn, Horner, & Dunlap, 2002; Smith & Sugai, 2000; Snell, Vorhees, & Chen, 2005; Umbreit, Ferro, Liaupsin, & Lane, 2006). Rather, such approaches may lead (at best) to short-lived, dull compliance. Their failing is in their inability to offer people skills and tools that become a part of themselves and that they can call upon over their lifetimes. In contrast, true positive approaches help people identify what they are trying to achieve through their problem behaviors and may teach new skills or behaviors to achieve the functions that

the person was attempting to achieve through undesirable behaviors; provide ready access to what individuals want or need; offer a full range of more meaningful and preferred activities; and/or assure that people have opportunities for control, mastery, and success.

How will our actions positively influence the person’s quality of life?

Too often, systems that support people with behavioral challenges inadvertently encourage over-reliance on behavior change technologies at the cost of personal relationships and a sense of personal contribution and belonging. Power should sit squarely with the person receiving support or, at a minimum, be far more evenly shared. The concern is that our service delivery systems appear predisposed to “quick fix,” control-oriented solutions.

In architecture, the guiding rule is that form should follow function; in human services, it could be argued that “form follows funding.” People are often served in outmoded models that were developed in response to the kinds of funding that were available at the time. Few people would choose to live in group homes with people they did not know or to spend their time in what some people refer to as “day-wasting centers,” but such models continue to predominate. Congregate settings such as these exist not because people desire to be supported in these ways but because it is difficult to convert from old models and overcome complacency. Additionally, when funding sources pressure administrators, and therefore staff, into quick fixes of difficult behaviors, the people employed by the system are inclined to deliver. As a result, conscientious employees feel compelled to move rapidly into identifying the problem behavior, isolating its characteristics, measuring it, and designing a program to reduce it with efficiency. Unfortunately, sometimes our haste to change behavior can impede our ability to ask basic questions we would hope someone would seek to answer with and for us if we were limited to asserting ourselves through problem behavior. For example, asking questions such as the following (Lovett, 1996) might prove valuable: (a) Who is this person? (b) What important needs would he or she identify as being unmet? (c) Given a full range of options, what would this person change about his or her life? (d) What has changed about this person’s life that may not have been consistent with what he or she would have chosen? and (e) With whom does this individual have meaningful relationships? Our primary line of inquiry should focus on understanding adverse aspects of the person’s life (including environments and demands) and then supporting the kinds of changes the person seeks in an effort to help him or her

achieve self-determined goals relevant to improving his or her self-perceived quality of life.

How have the people who know and care about the person participated in the process?

Clearly, many people with behavioral challenges can have difficulty articulating responses to questions like the ones above. Likely this is (at least in part) one reason why a person with a history of problem behavior may have resorted to extraordinary behaviors as a means of communication in the first place. If the person is unable to verbalize his or her own desires and frustrations, the people who know that person well are often able to come up with well-informed guesses (hypotheses) worthy of further exploration. In addition to talking with the person of concern, much can be learned when family members and the people who spend time with the individual day to day are asked to reflect on what they think the person's behaviors may be communicating or attempting to achieve. Functional assessments that are person-centered and culturally competent can help us to uncover important information and gain perspective. We must understand that people behave in dangerous or disruptive ways not because they are motivated to make the lives of others more difficult but because, from their perspective, it is the best way they know or have available to address their needs. We would do well to start with the assumption that it is unlikely the person's first choice is to engage in problem behavior. Given other opportunities that are equally efficient for achieving goals, most people willingly shift to less disruptive ways of accomplishing them. As such, our first response upon encountering a person with difficult behavior should not be to ask, "How can we apply technology to reduce this behavior?" or "How can we fix this person?" Rather, our focus when conducting a functional assessment and subsequently designing a behavior support plan should be on meaningful, collaborative attempts with the person and his or her family and friends to determine the nature of the distress being communicated through the problem behavior and on practical changes that can improve the quality and richness of life of all relevant parties.

To illustrate, Laura was described by her sister, mother, father, and teacher as a physically active girl who was very inquisitive. Her special education program was delivered within a self-contained classroom for students with significant disabilities. She was not included in some of the learning activities in which some of the other "higher functioning" children participated because the activities were thought by some members of the team to be too difficult for her. Based on Laura's perceived cognitive

limitations, Laura's teacher was directed to select a few activities that were better suited to her level of functioning. These included independently sorting items by color, putting together a puzzle, and matching objects to pictures on a grid. Laura's teacher noted that Laura showed curiosity about the more interesting and generally more physically active tasks of the other children and, as a result, she would wander around the classroom, disrupting the work of the other students. When she was directed back to her seat and her activities, Laura would often become upset, throwing her materials on the floor and occasionally pushing and hitting the teacher. Laura's teacher suggested to her principal that she felt that Laura really wanted to do what the other kids were doing, but Laura's teacher was directed to enlist the help of the school's behavior specialist to develop a program to get Laura to stay in her seat, attend to her work, and reduce Laura's aggressive behavior. Along with a long list of problem behaviors, the referral to the behavior specialist indicated that Laura was "noncompliant." Laura's teacher noted in her referral to the behavior specialist that she was reluctant to punish Laura for her behaviors. She stated that she hoped a program could be designed that would "enrich Laura's school experience by providing a reinforcer when she demonstrated the types of behaviors that were expected of her."

While somewhat brief in detail, the issues in Laura's situation should raise a number of questions. Simply because the technology exists to train Laura to be compliant does not necessarily make it the right thing to do. Attempting to change behavior in order for Laura to adapt to an unstimulating environment or inappropriate demands is, at best, suspect. An astute behavior change specialist would recognize Laura's behavior (at least in part) as a critique of her program. We could save so much time, money, and heartache if we simply become better at understanding (through listening to the person and with the collective insight of people closest to the person) what the people we support are telling us through their actions. It goes without saying, of course, that once we understand what the person is communicating through his or her behavior, it is incumbent upon us to advocate for the kinds of changes that would result in meaningful life improvements.

In addition to consulting with the people who know and care about the person in an effort to gain a better understanding of what might be motivating the problem behavior, it is also important to have these conversations because family members may well be involved in implementing any behavioral approaches that are established. Albin et al. (1999) described a model for establishing the degree to which behavior programs are a good fit for the

culture of the family; the authors call this *goodness-of-fit*. When family members are included in the identification of the functions of behaviors, when they understand the purpose behind behavioral interventions, and when the strategies called for are compatible with the values, skills, and routines of the family, there is far greater likelihood that the strategies will be implemented and, therefore, that the approach will be effective.

How will the approach that is used affect the people implementing the procedures and others?

There is a certain irony in the fact that in an attempt to reduce aggressive and impulsive behavior many practitioners employ techniques that have been demonstrated to result in the same kinds of behaviors that they were intended to decrease. Some caregivers, convinced that behavior change will be affected by imposing increased restrictions, rationalize the relevance of these practices by making such statements as, "These strategies are for the person's own good," "We couldn't serve people as difficult as him without these tools," or "You don't know what people like this are like." Caregivers can become increasingly detached from the people they are to serve as a result of participating in restrictive and coercive interventions. It is almost impossible to have both a connected and nurturing relationship while increasingly asserting control. Detachment can lead to depersonalization, which can be dangerous for both the person and his or her caregivers. Various forms of abuse can occur when a caregiver does not think of the person receiving support as a fully valued individual.

While the field is increasing its understanding of the ill effects of coercion on people with problem behavior, we are only beginning to understand the negative effects that providing demeaning and coercive programming may have on the staff who implement these procedures. The tragic irony of this juxtaposition is that the use of coercive techniques likely results in the absence of a personal and caring relationship when personal and caring relationships are often the very thing people with challenging behaviors most need to change their behavior.

In addition to the impact that this kind of intervention can have on caregivers, we also inadvertently may compromise the public's perception of people when our treatment implies that they are dangerous, unpredictable people whose unusual behaviors need to be controlled through extraordinarily manipulative means. The depersonalization that permits coercive interventions to be used leads to further depersonalization and isolation as observers become more wary of the techniques' recipients.

If the tables were turned, would you use the interventions selected with a family member or friend?

Even programs that are based in reinforcement theory can become overly controlling. For example, Dylan, who was 9 years old and had been diagnosed with autism, loved comic books. Each day when he returned home from school, Dylan would spend an hour or so flipping through his favorites. At the school's recommendation, his parents had a meeting with the school psychologist to design an intervention program for Dylan's behavior of destroying materials and being disruptive at school. The psychologist asked Dylan's parents to list those things Dylan found enjoyable at home. Both immediately thought of his comic books. As a result, it was recommended that access to his comic books at home be made contingent on Dylan bringing home a note from his teacher saying that he had had a good school day. The school psychologist was taken aback when the program he had recommended was not supported by other members of Dylan's school team. "It's completely positive!" he insisted. Requiring people to earn access to things that had previously been available to them or that are readily available to their peers should prompt serious reconsideration.

Simply stated, programs that rely predominantly on contrived contingency manipulation can be short-sighted and tend to become overly intrusive. It is not typically necessary to implement complicated schedules of contingent reinforcement to get people to do things they find meaningful in the first place. When we are tempted to implement some complex schedule of contingencies, it is probably a good time to step back and look at the big picture—to ask ourselves if there are not meaningful changes that this person could be supported to make in his or her life (i.e., address the setting events for problem behavior by helping the person to live a fuller life). The main message so many behavior programs seem designed to communicate is "We're in charge and you're not." Rather, we should be attempting to communicate that the person's preferences, goals, and feelings are paramount and that we are here to help in their pursuit.

How will the behavioral interventions minimize the likelihood of crisis?

When positive behavioral approaches are used, situations that escalate to crises are significantly reduced. In October 1998, the *Hartford Courant* newspaper documented the occurrence of 142 restraint deaths between 1988 and 1998 (Weiss, 1998). The pace of these has not

slowed: Two people died in restraint the month this article was written. In none of these cases was the staff person or teacher reportedly motivated by intent to do harm. To the contrary, when interviewed, staff members felt that they had used these procedures “for the person’s own good.” The circumstances leading up to these deaths describe a litany of power struggles. One man was restrained when his behavior escalated after he asked to watch television and was told that TV was not allowed during the day; one man became upset after he was denied access to the bathroom because it was not “bathroom time”; one woman died as a result of being unwilling to hand a family photograph over to staff. In each case, a simple conflict escalated to a power struggle and resulted in a tragic end; in each case, the person was a victim of an overly controlling and coercive program.

Although these cases represent the worst imaginable result, power struggles such as these are too common. The *Hartford Courant* commissioned a statistical estimate from the Harvard Center for Risk Analysis which estimated that between 50 and 150 deaths from the use of restraint occur each year—that is, 1 to 3 deaths per week—and even this represents only a tiny portion of the power struggles that occur routinely in controlled settings. When power is persistently taken from someone, it is a natural response for that person to act in self-defense in an attempt to reassert control. Rather than difficult behaviors being viewed as an indication to rethink the necessity for restricting people’s right to control their own lives, they are often unfortunately and simplistically viewed as signaling the need for even more stringent controls. Behaviors escalate further in response, and the cycle goes unbroken, often until tragedy results—if not in loss of life, surely in the unnecessary loss in quality of life.

Conclusion

As a field, it is time to move beyond overly restrictive and coercive practices, not only because they are dehumanizing but also because they rarely lead to durable positive change. Rather than seeking ways to control people (in the name of treatment and/or intervention), we should be seeking ways to better understand them, to communicate with them, and to work with them toward achieving fulfilling lives. In the assessment and intervention design process one will generally never go wrong by asking, “You seem unhappy. Is there anything I can do?” or “You seem to need something. Can I help?” When people feel valued and included they are much less likely to behave in ways that are challenging to the people around them. As helpful as technology can be

(and, to be clear, technologies such as functional behavior assessment and subsequent supports can be invaluable), it is not enough to design behavior programs that avoid the use of aversive procedures and restraints but depend heavily on other coercive means. As family members, advocates, staff, teachers, researchers, and others who work in the field of behavior change, we have a responsibility to the people we serve (and to ourselves) that has less to do with getting others to act in predetermined ways and much more to do with supporting people to become increasingly self-directed and fulfilled.

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- Nancy R. Weiss**, MSW, is codirector of the National Leadership Consortium on Developmental Disabilities at the University of Delaware (www.nlcdd.org). She is the former executive director of TASH.
- Tim Knoster**, EdD, is an associate professor in exceptionality programs at Bloomsburg University, executive director of the Association for Positive Behavior Support, and cochair of TASH's Positive Approaches Committee.